Bliss COLLECTIVE

Caregiver

Caregivers, Families, and Care Partners

Created With Caregivers in Mind

We see you. We hear you. We appreciate you.

Caregiving is one of the most profound acts of love and support a person can provide. Yet it is often invisible work: demanding, emotional, and deeply important. Whether you're supporting a spouse, parent, child, sibling, or friend through cancer diagnosis and treatment, your role matters. You are not just a helper; you are an advocate, a coordinator, an emotional anchor, and often, a voice for someone navigating one of the most difficult seasons of their life.

But here's what we know: **caregivers often put their own needs last.** You're managing medical appointments, transportation, medications, finances, and emotional support, sometimes while managing your own stress, work, family responsibilities, and fear. You may be dealing with medical jargon you don't understand, insurance barriers, and the weight of helping someone make life-altering decisions. You might be navigating cultural expectations about what caregiving looks like or feeling unprepared to advocate when something feels wrong.

You deserve support, information, and recognition.

This toolkit was created with you in mind. It's designed to help you feel informed, prepared, and empowered as you navigate cancer care a nd clinical trials alongside your loved one. Whether you're helping someone understand their diagnosis, supporting their treatment decisions, advocating for their needs, or simply trying to take care of both of you—this toolkit is here to help.

In this toolkit, you will find:

- Real information about your role and support available to you
- Practical strategies for managing appointments, medications, and communication
- Questions to ask the care team
- Ways to advocate for your loved ones and protect your own well-being
- Resources and support services

UNDERSTANDING THE BARRIERS

Why Caregiver and Family Support Matters

Caregiving can be overwhelming—especially when navigating cancer and clinical trials.

Caregiving can affect emotional well-being, finances, work responsibilities, and overall quality of life. Many caregivers experience stress and may benefit from additional support.

Additional Barriers Caregivers Face:

- **Emotional stress and burnout** from managing fear, grief, and advocacy while maintaining composure
- **Financial strain** from treatment costs, lost income, and travel expenses
- **Communication barriers** due to medical jargon, language differences, or health literacy gaps
- **Medical mistrust and cultural factors** that affect willingness to participate in clinical trials
- **Feeling unprepared** to advocate or ask the right questions
- **Cultural expectations** and pressure to handle caregiving alone or without seeking support
- **Social isolation** and limited access to peer support and mental health services

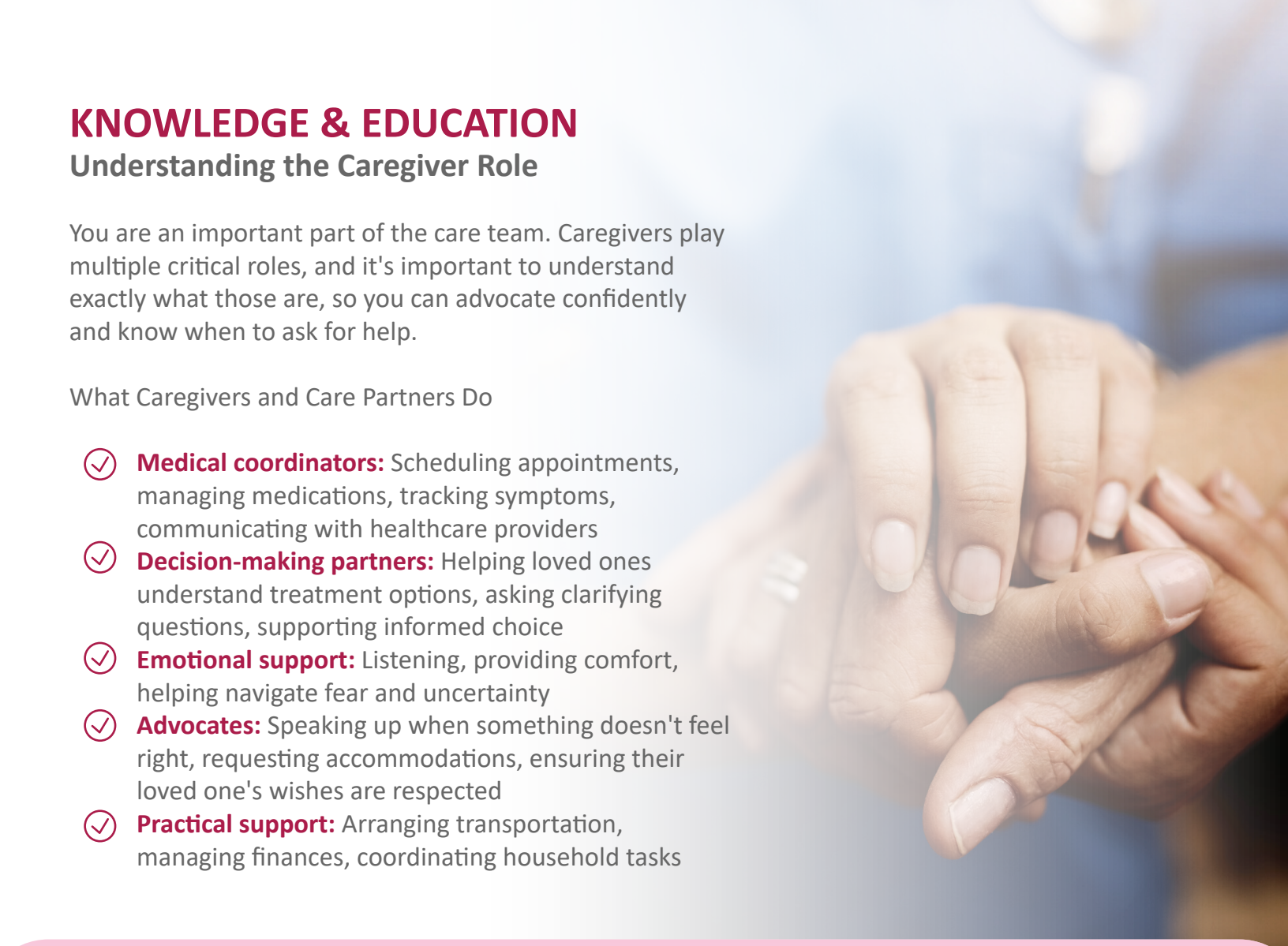
The Good News:

Many of these barriers can be addressed with the right information, tools, and support. This toolkit is designed to help you navigate them.

KNOWLEDGE & EDUCATION

Understanding the Caregiver Role

You are an important part of the care team. Caregivers play multiple critical roles, and it's important to understand exactly what those are, so you can advocate confidently and know when to ask for help.



What Caregivers and Care Partners Do

- **Medical coordinators:** Scheduling appointments, managing medications, tracking symptoms, communicating with healthcare providers
- **Decision-making partners:** Helping loved ones understand treatment options, asking clarifying questions, supporting informed choice
- **Emotional support:** Listening, providing comfort, helping navigate fear and uncertainty
- **Advocates:** Speaking up when something doesn't feel right, requesting accommodations, ensuring their loved one's wishes are respected
- **Practical support:** Arranging transportation, managing finances, coordinating household tasks

Different Types of Caregivers

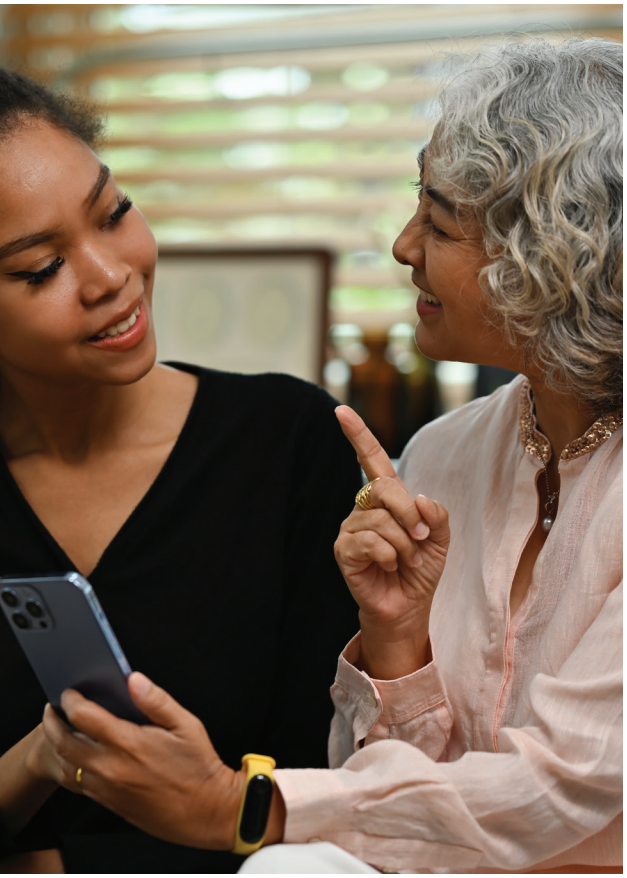
Caregivers come in many forms: spouses, adult children, parents, siblings, friends, neighbors, or faith community members. Each brings unique perspectives and challenges. Whether you're a primary caregiver providing intensive daily support or a secondary caregiver offering occasional help, your role matters.

Understanding Clinical Trials

A clinical trial is a research study that tests whether a new treatment is safe and effective. It involves carefully monitored research protocols, informed consent processes, and regular check-ins to assess how participants respond. Clinical trials are critical to advancing cancer care; participation is always voluntary, and participants can withdraw at any time without affecting their regular medical care.

Myths vs. Facts About Clinical Trials

Myth	Fact
Clinical trials are only for people with no treatment options.	Clinical trials are available at various stages of treatment and for people at all stages of disease.
Participants in clinical trials receive placebos and no real treatment.	Most cancer trials compare a new treatment to the standard treatment, not a placebo. If a placebo is used, participants still receive standard care.
Clinical trials are dangerous and have no safeguards.	Rigorous safety monitoring, ethics committees (Institutional Review Boards), and informed consent to help protect participants.
You can't leave a clinical trial once you start.	Participation is always voluntary. Participants can withdraw at any time without affecting their care.



Understanding Informed Consent

Informed consent is a process that helps patients understand the purpose of the study, what participation involves, potential risks and benefits, and their rights before deciding whether to participate. You and your loved one have the right to ask questions, take time to decide, and understand everything before signing. If something isn't clear, ask the research team to explain it differently.

Understanding Patient Rights

Patients have the right to understand their diagnosis and treatment options, ask questions, refuse treatment, seek second opinions, access their medical records, and receive respectful, culturally informed care. Your role as a caregiver is to help ensure these rights are upheld and that your loved one feels comfortable exercising them.

Caregiver Communication Tips

Taking notes during appointments – Write down treatment plans, medication names, side-effect management strategies, and next steps. Ask for clarification on anything you don't understand.

Track symptoms and side effects – Keep a log of when side effects occur, their severity, and any patterns. This information helps the care team adjust treatment if needed.

Organize medications – Keep a current list of all medications, doses, and schedules. Bring this to every appointment.

Ask questions without hesitation – There are no "wrong" questions. If you don't understand something, ask. Ask again if needed.

Support shared decision-making – Help your loved one think through treatment options by summarizing what you've learned, asking clarifying questions, and ensuring they feel heard in decisions about their care.

ACTION STEPS

Ways to Support Yourself and Your Loved One Know Your Role — But Protect Your Peace

Setting Boundaries: It's okay to say no. You cannot pour from an empty cup. Decide what you can realistically provide and communicate this clearly. If you can't attend every appointment, that's okay. If you need a break from caregiving, that's okay. Boundaries are not selfish; they are essential.

Asking for Help: Other people want to help but often don't know how. Be specific: "Could you bring us a meal on Tuesday?" or "I need someone to drive my mom to her appointment on Friday." Making specific requests is easier for people to say yes to.

Accepting Support: Let people help. Whether it's a meal, a listening ear, or financial support, accepting help is not a weakness—it's wisdom.

Taking Breaks Without Guilt: You need rest, time alone, and moments away from caregiving. Schedule regular breaks to rest and recharge. Caring for yourself helps you continue caring for someone else.

Prepare for Appointments

Before the Appointment:

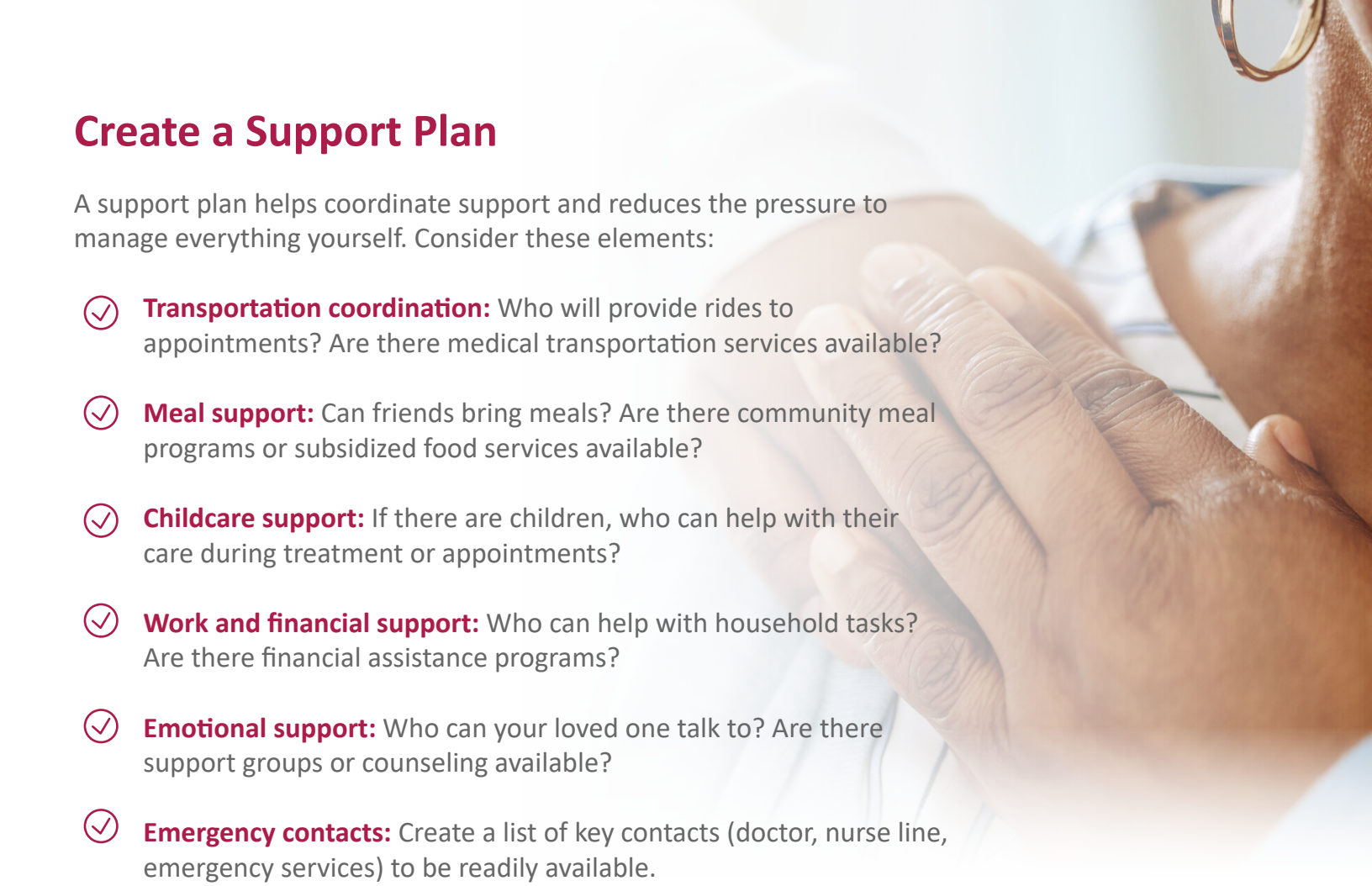
- Write down questions and bring them with you
- Bring a complete list of current medications and supplements
- Bring insurance cards and photo ID
- Review notes from the previous appointment
- Write down any new symptoms or side effects

During the Appointment:

- Introduce yourself and your role to the care team
- Ask if you can stay in the room if your loved one is comfortable with this
- Take notes on treatment plans, next steps, and any changes to medications
- Write down the names of any new healthcare providers you meet
- Ask about after-hours support or emergency contacts

After the Appointment:

- Clarify next steps before leaving: What happens next? When? Who should we contact with questions?
- Update your medication list if changes were made
- Request printed summaries or follow-up documentation
- Schedule the next appointment before leaving



Create a Support Plan

A support plan helps coordinate support and reduces the pressure to manage everything yourself. Consider these elements:

- **Transportation coordination:** Who will provide rides to appointments? Are there medical transportation services available?
- **Meal support:** Can friends bring meals? Are there community meal programs or subsidized food services available?
- **Childcare support:** If there are children, who can help with their care during treatment or appointments?
- **Work and financial support:** Who can help with household tasks? Are there financial assistance programs?
- **Emotional support:** Who can your loved one talk to? Are there support groups or counseling available?
- **Emergency contacts:** Create a list of key contacts (doctor, nurse line, emergency services) to be readily available.

Advocate When Something Feels Wrong

Trust Your Instincts: If you notice something isn't right—an unusual side effect, a communication gap, or a sense that something was misunderstood—speak up. You know your loved one best.

Speak Up Respectfully: Use phrases like "I've noticed..." or "I'm concerned about..." to start conversations. Share specific observations, not generalizations.

Request Clarification: Ask the care team to explain again if you don't understand something. Ask for printed materials or educational resources.

Seek Second Opinions: If you have concerns about a treatment recommendation, it's reasonable to ask for a second opinion. Many hospitals provide this service.

Request Interpreters or Support Services: If there are language barriers or accessibility needs, ask the hospital to provide interpreters or accommodations. These are typically free services.

QUESTIONS TO ASK

Questions for Your Care Team

These questions are organized by category. Feel free to write them down, bring them to appointments, and add your own questions as they arise.

Questions About Treatment

- What is the diagnosis, and what does it mean?
- What treatment options are available?
- Why is this treatment recommended? What should we expect during treatment (duration, frequency, location)?
- What side effects should we watch for?
- How will we know if the treatment is working?
- What should we do if side effects occur or feel severe?
- Who do we contact after hours if there's an emergency? Can you provide written information about the treatment?

Questions About Clinical Trials

- Why might this clinical trial be a good option?
- What is this clinical trial testing?
- How long will participation last?
- How often are visits required?
- What does the trial involve (procedures, tests, medications)?
- What are the potential risks and benefits?
- What happens if we decide to leave the trial?
- What costs are covered by the trial, and what aren't?
- Can caregivers attend appointments?
- Will there be compensation for travel or time?
- How will my loved one's safety be monitored?

Questions About Support Services

- Is transportation support available?
- Are there financial assistance programs?
- Are mental health services available for patients and caregivers?
- Are there support groups available?
- Can we speak with a patient navigator or social worker?
- What resources are available in my language?
- Are there any nutritionists or other specialists we can see?

SAMPLE PHRASES & CONVERSATION STARTERS

What to Say During Appointments

These questions are organized by category. Feel free to write them down, bring them to appointments, and add your own questions as they arise.

When You Don't Understand Something:

- "Can you explain that in simpler language?
- "II want to make sure I understand. Can you walk me through that again?
- "What does that term mean in everyday language?
- "Could you write that down for me?

When You Want to Discuss Concerns:

- "I've noticed [specific symptoms]. Is this something we should be concerned about?
- "What happens if we want a second opinion?
- "Can we take a moment to discuss the risks and benefits again?
- "I want to make sure we understand all available options.

When You Want to Understand Your Role:

- "What can I do as a caregiver to best support treatment?
- "What support services are available for caregivers?
- "Can we review what to watch for and who to call if there are problems?
- "Can you help us understand the next steps?

When You Need Follow-Up:

- "Who should we contact if we have questions after we leave today?
- "When will we know the results?
- "Can we get that in writing?
- "What's the best way to reach your office if we need to talk before our next appointment?

TIGER TIPS

Practical Tips for Caregivers

Tip #1

Be Honest About Burnout

Caregiving can be physically and emotionally demanding. Feeling tired, overwhelmed, frustrated, or uncertain at times is common and does not mean you are failing as a caregiver. Pay attention to signs of burnout and seek support before stress becomes overwhelming. Whether it's a support group, counselor, patient navigator, family member, or trusted friend, asking for help is a sign of strength. Taking care of yourself helps you continue supporting your loved one.

Tip #2

Track Important Information

Keep medications, symptoms, appointments, and emergency contacts organized. Use a notebook, folder, or digital app. Create a list of all medications with names, doses, and schedules. Write down when side effects occur and how severe they are. This information helps the care team provide better care and helps you stay organized.

Tip #3

Ask Questions

You deserve clear communication and respectful care. There are no "stupid" questions in healthcare. If you don't understand something, ask. If an answer doesn't make sense, ask again. If you want to understand the reasoning behind a recommendation, ask. Your questions help ensure you and your loved one are informed and empowered.

Tip #4

Take Care of Yourself Too

Your health matters. Eat well, get rest, move your body, and do things that bring you joy. Schedule doctor appointments for yourself. Tell someone if you're struggling emotionally. Taking care of yourself is not selfish—it's essential. You cannot pour from an empty cup, and your loved one needs you to be well.

WHAT THE LAW SAYS

Understanding Caregiver and Patient Rights

Disclaimer: This section provides general educational information and is not legal advice. Laws vary by state and country. For specific legal guidance, consult an attorney or your state's legal aid organization.

Privacy and HIPAA Basics

The Health Insurance Portability and Accountability Act (HIPAA) protects patient medical privacy. Healthcare providers cannot share a patient's medical information without written permission, with some exceptions for family members involved in care. If you're a caregiver, ask your loved one to sign a HIPAA authorization form allowing the care team to discuss their health with you. This ensures you're included in care decisions.

Caregiver Participation Permissions

Your loved one can decide whether you're present during appointments, medical discussions, or procedures. Respect their wishes while advocating for your role as a caregiver. If language barriers exist, request interpretation services. If physical accessibility is needed, request accommodations.

Patient Rights During Clinical Trials

Research participants have the right to:

- Full, understandable information about the trial
- Know all risks and potential benefits
- Ask questions without pressure
- Take time to decide before signing consent forms
- Withdraw from the trial at any time without affecting their regular care
- Know how their personal information will be protected
- Compensation for injuries related to the trial (in most jurisdictions)

Right to Interpreters

Hospitals and healthcare providers are required to provide free interpretation services if language is a barrier. Request an interpreter when scheduling appointments or upon arrival. Do not rely on family members or untrained staff for medical interpretation, as this can lead to misunderstandings.

Right to Second Opinions

Patients have the right to seek second opinions on diagnoses and treatment recommendations. Most hospitals and insurance companies support this practice. Request your medical records to share with the second-opinion provider.

Employment protections and leave policies vary. Speak with your employer's human resources department or a legal advisor to understand available options.

RESOURCES & NEXT STEPS

You Are Supported

Support exists. Whether you need practical assistance, emotional support, information, or community connection, these resources can help.

National Caregiver Support Organizations

- Caregiver Action Network – Information, support groups, and advocacy resources for caregivers
- Family Caregiver Alliance – Caregiver support, counseling, and care planning resources
- AARP Caregiver Resource Center – Tools, tips, and support for family caregivers

Clinical Trial Resources

- ClinicalTrials.gov – Search for clinical trials and learn about trial details and eligibility
- National Cancer Institute (NCI) Cancer Information Service – Information about cancer and clinical trials
- National Institutes of Health (NIH) – Information about clinical trial protections and participant rights

Cancer-Specific Support

- American Cancer Society – Cancer information, support groups, and resources for patients and caregivers
- Cancer Support Community – Free emotional support, educational programs, and support groups

Transportation Assistance

- American Cancer Society (transportation programs) – Free or low-cost rides to treatment
- NPAF - National Patient Advocate Foundation – Connect with patient advocates and local resources
- Local Area Agencies on Aging (AAA) – Transportation services for seniors and caregivers

Financial Support

- National Patient Advocate Foundation – Financial assistance programs and caregiver resources
- HealthWell Foundation – Co-payment and insurance premium assistance
- Patient Advocate Foundation – Financial assistance and caregiver support
- Medication Assistance Programs – Many pharmaceutical companies offer free or reduced-cost medications for eligible patients

Mental Health and Counseling Support

- National Alliance on Mental Illness (NAMI) Helpline (1-800-950-6264) – Mental health support and resources
- Psychology Today Therapist Finder – Find therapists in your area
- Your hospital or cancer center's social work department – Often provides free or low-cost counseling

Community Organizations

Local community organizations, faith-based groups, meal-planning services, and neighborhood associations often provide support to caregivers and families.
Check with your local:

- Community Centers
- Libraries (many offer free health resources)
- Places of Worship
- Neighborhood groups
- School or workplace employee assistance programs (EAP)

GLOSSARY

Understanding Common Terms

Healthcare and research use a lot of terminology. Here are plain-language definitions of common terms you'll encounter:

Biomarker – A biological characteristic or marker (often found through blood tests or biopsies) that helps doctors understand how a disease may progress and which treatments might work best.

Caregiver – A person who provides care, support, and assistance to someone with an illness or health condition. This may include medical, logistical, emotional, or practical support.

Clinical Trial – A research study that tests whether a new medical treatment or intervention is safe and effective.

Clinical Trial Phase – Clinical trials progress through phases (Phase 1, 2, 3, 4). These stages of a clinical trial are designed to answer different questions about safety, effectiveness, and long-term use.

Genomic Testing – Testing that examines a person's genes or cancer cells' genes to identify mutations or characteristics that may affect treatment options.

Informed Consent – A process in which a patient or research participant receives complete, understandable information about a treatment or trial—including risks, benefits, and alternatives—and freely agrees to participate.

Palliative Care – Medical care focused on relieving pain, managing symptoms, and improving quality of life for people with serious illnesses. Palliative care can be provided alongside curative treatment.

Patient Navigator – A healthcare professional who helps patients navigate the healthcare system, understand their condition, coordinate care, and connect with resources.

Shared Decision-Making – A process where patients, caregivers, and healthcare providers work together to discuss options and make treatment decisions that reflect the patient’s needs, values, and preferences.

Side Effect – Any effect or reaction from a medication or treatment other than the intended therapeutic effect. Side effects may be mild or severe, and temporary or long-term.

Survivorship – The period of time after a cancer diagnosis, including active treatment, recovery, and life after treatment. Survivorship includes both emotional and physical recovery.

CLOSING MESSAGE

Caring for Others Starts with Supporting Yourself Too

You've picked up this toolkit because you care deeply. You're trying to be the best support possible for your loved one while navigating complex medical decisions and emotional terrain. This deserves recognition.

Caregivers matter. Your role is not invisible, even when it feels that way. Your presence, your questions, your advocacy, and your love make a real difference in your loved one's care experience and health outcomes.

You deserve support and information. It is not selfish to prioritize your own well-being. You cannot pour from an empty cup. Taking care of yourself enables you to show up more fully for your loved one.

Advocacy may help improve communication and care coordination. Speaking up, asking questions, and sharing concerns doesn't make you difficult. It makes you an engaged partner in care. Caregivers who advocate for clear communication and comprehensive support help improve outcomes for their loved ones.

Community matters. You are supported in this journey. Other caregivers understand the unique challenges you're facing. Support groups, online communities, organizations, and the people in your life who care about you are resources waiting to be tapped.

As you move forward in this journey—whether your loved one is newly diagnosed, considering a clinical trial, actively undergoing treatment, or in recovery—know that resources, support, and community exist.

We see you. We hear you. We appreciate you.

SPARK
Advancing Equity in Research

SPARK is committed to empowering individuals through education, trusted resources, and equitable access to cancer clinical trials and personalized cancer care.

Bristol Myers Squibb®

Tigerlily Foundation
Beauty. Strength. Transformation.

Scan for more resources!